

An Automated Epilepsy Patient Registry

Chiang S. Jao, Ph.D., Daniel B. Hier, M.D., Jesse E. Taber, M.D.,
Steven U. Brint, M.D., and Melissa J. Tobin, B.S.

Department of Neurology, College of Medicine, University of Illinois at Chicago
Chicago, IL 60612

ABSTRACT

The traditional medical record is a mixture of handwritten physician notes, handwritten notes by other health professionals, some typed notes, and typed laboratory as well as radiology reports. The traditional medical record does not guarantee completeness, uniformity, or legibility. Furthermore, the traditional medical record is usable by only one user at a time. Two potential replacements have emerged to replace the traditional medical record: a fully digital medical record and an imaged medical record. The fully digital record is very flexible and easy to search but requires considerable investment in data entry. The imaged (scanned) medical record has lower demands for data entry but is more difficult to search and index.

The Epilepsy Clinic at the University of Illinois at Chicago has operated continuously for more than 45 years and has over 1,400 patients enrolled. There are more than 3,000 patient visits annually. Our goal was to create an automated patient epilepsy registry for the Epilepsy Clinic that would have the following desirable features: (1) Support collection of uniform data on each patient visit. (2) Minimize operator data entry time. (3) Create a fully searchable patient database that would support both database queries as well as statistical analysis and graphing of data. (4) Create a database accessible to multiple users simultaneously.

We have converted part of the medical record for all patients in the Epilepsy Clinic into a relational database. The database currently has two linked files: a "Demographics" file and a "Return Visit" file. The files are linked by a unique medical record number. Only one entry in the "Demographics" file is made for each patient in the Epilepsy Clinic. Each record includes the demographics data of a patient. An entry into the "Return Visit" file is made for each patient visit. Data collected includes Subjective (seizure frequency, side effects), Objective (physical examination, drug levels, EEG findings), Assessment (diagnosis), and Plan (drug dosages, etc.).

We designed the medical record for the Epilepsy Clinic as multiple entries into a relational database. We used TeleForm[®] to construct a structured encounter form for the neurologist to use for each return visit of an epilepsy patient. TeleForm[®] assigns a unique form identification number to each form. This identification number permits the evaluation program to identify the scanned form as a "Demographics Form" or an "Epilepsy Return Visit Form." TeleForm[®] supports a variety of field types in data entry, including alphabetic and/or numeric constrained print field, choice field, image zone and, non-printed entry field. The choice field allows the user to select either a single item or multiple items listed on the form. The image zone allows storage of stamped marks (such as impressions of patient ID plates) as a pictorial record. There are four small squares located at four corners of each sheet to identify the data entry area in a form and to ensure form alignment.

After the neurologist completes the form(s), the operator places multiple entry forms on the scanner's automatic feeder. TeleForm Manager[®] drives the scanner to scan multiple forms. Forms are evaluated based on their identification numbers. After evaluation by TeleForm[®], data are stored into the database file in a dBase IV format. Questionable data is held in a suspended queue for manual verification.

We have created an automated patient registry for the Epilepsy Clinic at the University of Illinois. The Epilepsy Patient Registry is implemented on an IBM Token-Ring LAN to allow multiple users to access the database simultaneously. This record supplements but does not replace the traditional medical record. Automated data entry into an Epilepsy Patient Database has accomplished several goals: (1) Improved consistency and legibility of the medical record. (2) Efficient data entry which capitalizes on OCR software. (3) Availability of data in the medical record to multiple user simultaneously. (4) Creation of a flexible patient database which is used to support both clinical decision-making and clinical research.